

ICICE Baseline Interview For CHF Patients



Copyright © RAND 2001. All rights reserved. RAND: Santa Monica, CA.

04/26/2001

~~~~~  
INTRODUCTION OF STUDY TO RESPONDENT  
~~~~~

Hello, my name is [FIRST AND LAST NAME]. May I speak with [R's NAME]?

I'm calling to follow up on a letter we sent you about research [FILL SITE NAME] and RAND are conducting. The letter was mailed on [DATE] and mentioned that an interviewer from RAND would be calling to request a telephone interview and to answer any questions you have about this study.

Do you remember getting the letter?

IF YES, GO TO STUDY
IF NO, GO TO NOLET

For respondents who don't remember getting letter:

The letter was from [FILL SITE CO-SIGNER] OF [FILL SITE NAME] and Dr. Emmett Keeler, a researcher at RAND. The letter invited you to take part in research to improve the care of patients who receive care for heart failure from [fill SITE NAME]. The letter mentioned two telephone interviews and your health care records.

We are calling now to ask you to take part in the first telephone interview.

INTERVIEWER: HIT ENTER AND CONTINUE

Of course participation in the study is voluntary. You can stop the interview or refuse to answer a question at any time. Your decision to take part will not affect the care you get from [FILL SITE NAME] in any way. RAND will not give your doctor a copy of the answers you give in the interview. Any and all study results will be reported only at the group level. No individual person's information will be published separately in any report of results. The information we give to [FILL SITE NAME], to help them improve the care they give to people with heart failure will be limited to group summaries and statistics.

We can't pay you for your time, but we will send you \$10 as a token of our thanks for taking part in this interview. Your answers to the interview will be combined with information from your health care records from [FILL SITE NAME]. We have found that the additional information we can collect from your health care records is very valuable as it helps us to complete the picture of your health and the care you get.

All respondents get this screen:

Our records indicate that you have heart failure. Doctors sometimes call this congestive heart failure, an enlarged heart, or fluid in the lungs. Your doctors may have used one of these names or a different name to describe your heart condition. In our study interview we use the words heart failure as the name of this condition. Is this a good time to start the interview?

IF R SAYS "I DON'T HAVE HEART FAILURE, I HAVE FIBRILLATIONS SAY: Whenever I use the word heart failure, in the interview, think of your fibrillations. (Is this a good time to start?).

IF NEEDED: Your name and contact information was given to RAND by [FILL SITE NAME], because you have had care for heart failure.

IF NEEDED: The goal of this study is to find out about any other health problems you may have, and the services and treatment you and others in this study receive. The interview has questions about your health and the care you got from [FILL SITE NAME] as well as questions about other health conditions, your daily activities and your feelings and emotions. It should take about 30 minutes.

IF NEEDED: The length of the interview varies depending on you and your experiences. It can take less than 30 minutes.

IF NEEDED: We don't have to do the whole interview right now, we can go for a few minutes and then I can call you back at another time to complete the interview.

Use advance letters and Question and Answer sheet to answer any questions.

- 1 Continue with interview
- 2 R refuses to take part
- 3 R requests remail of letter before deciding to take part (Set call back and complete remail request slip)
- 4. R says he/she doesn't have heart failure.
- x Schedule a call back

For all respondents, who say they don't have sampled condition:

We'll check our records again. Another interviewer may call you back in the next week or so to follow-up.

[Case goes to supervisor for a review and verification]]

For all respondents, before any interview is started:

Before we begin, I need to tell you that for the purposes of quality control, my supervisor may monitor this call.

A. Health-related Quality of Life

These first questions ask about your health and how your heart failure affects your life.

SOURCE: Medical Outcomes Study (MOS) Short-Form 12: *How to Score the SF-12 Physical and Mental Health Summary Scales*, J.E. Ware, M.A. Kosinski, and S.D. Keeler, The Health Institute, New England Medical Center, 2nd Ed., 1995.

CHFA1

1. In general, would you say your health is:

- 5 Poor
- 4 Fair
- 3 Good
- 2 Very good
- 1 Excellent

CHFA2

2. Now I'm going to read a list of activities that you might do during a typical day. As I read each item, please tell me if your health now limits you a lot, limits you a little, does not limit you in these activities.

First, moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf. Does your health now limit you a lot, limit you a little, or not limit you at all?

If R says "I don't do activity," probe: Is that because of your health?

- 1 Yes, limits a lot
- 2 Yes, limits a little
- 3 No, not limited at all

CHFA3

3. Climbing several flights of stairs. (Does your health now limit you a lot, limit you a little, or not limit you at all?)

If R says "I don't do activity," probe: Is that because of your health?

- 1 Yes, limits a lot
- 2 Yes, limits a little
- 3 No, not limited at all

CHFA4

4. The following two questions ask you about your physical health and your daily activities.

During the past 4 weeks, have you accomplished less than you would like as a result of your physical health?

- 5 Yes
- 1 NO

CHFA5

5. During the past 4 weeks, were you limited in the kind of work or other regular daily activities you do as a result of your physical health?

- 5 Yes
- 1 NO

CHFA6

6. The following two questions ask about your emotions and your daily activities.

During the past 4 weeks, have you accomplished less than you would like as a result of any emotional problems, such as feeling depressed or anxious?

- 5 Yes
- 1 NO

CHFA7

7. During the past 4 weeks, did you not do work or other regular daily activities as carefully as usual as a result of any emotional problems, such as feeling depressed or anxious?

- 5 Yes
- 1 NO

CHFA8

8. During the past 4 weeks, how much did pain interfere with your normal work, including both work outside the home and housework. Did it interfere:

- 1 Not at all
- 2 A little bit
- 3 Moderately
- 4 Quite a bit
- 5 Extremely

CHFA9

9. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities like visiting with friends or relatives? Has it interfered:

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

CHFA10

10. These next questions are about how you feel and how things have been with you in the past 4 weeks. As I read each statement, please give me the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks have you felt calm and peaceful? Was it:

- | | |
|--------------------------|------------------------|
| 1 All of the time | 4 Some of the time |
| 2 Most of the time | 5 A little of the time |
| 3 A good bit of the time | 6 None of the time |

CHFA11

11. How much of the time during the past 4 weeks did you have a lot of energy? (Was it:)

- | | |
|--------------------------|------------------------|
| 1 All of the time | 4 Some of the time |
| 2 Most of the time | 5 A little of the time |
| 3 A good bit of the time | 6 None of the time |

CHFA12

12. How much of the time during the past 4 weeks have you felt downhearted and depressed? Was it:

- | | |
|--------------------------|------------------------|
| 1 All of the time | 4 Some of the time |
| 2 Most of the time | 5 A little of the time |
| 3 A good bit of the time | 6 None of the time |

CHF-Specific Quality of Life Measures

CHFA13

13. These next questions ask more specific questions about how your heart failure has affected you and kept you from living the way you wanted to during the past 4 weeks.

During the past 4 weeks, how much of the time did your heart failure stop you from doing the things you wanted to do because you had to sit or lie down to rest during the day? Was it:

- 1 All of the time
- 2 Most of the time
- 3 Some of the time
- 4 A little of the time
- 5 None of the time

CHFA14

14. (During the past 4 weeks,) how much of the time did your heart failure stop you from doing the things you wanted to do because you were short of breath? Was it:

- 1 All of the time
- 2 Most of the time
- 3 Some of the time
- 4 A little of the time
- 5 None of the time

CHFA15

15. (During the past 4 weeks,) how much of the time did your heart failure stop you from doing the things you wanted to do because you were tired, fatigued, or low on energy? Was it:

- 1 All of the time
- 2 Most of the time
- 3 Some of the time
- 4 A little of the time
- 5 None of the time

CHFA16

16. (During the past 4 weeks,) how much of the time did your heart failure make it difficult for you to sleep well at night? (Was it:)

- 1 All of the time
- 2 Most of the time
- 3 Some of the time
- 4 A little of the time
- 5 None of the time

[TRAINING AND Q BY Q ISSUE: Respondents who say they don't do a task because of heart failure should be coded as 5—so difficult you could not do it.]

Next, I want you to tell me how much difficulty you had doing daily activities during the past 4 weeks because of your heart failure.

CHFA17

17. How difficult was it for you to get dressed because you felt short of breath or tired? Was it:

- 1 Not difficult at all
- 2 A little difficult
- 3 Somewhat difficult
- 4 Very difficult
- 5 So difficult you could not do it

CHFA18

18. How difficult was it for you to walk on level ground at a normal pace because you felt short of breath or tired?

- 1 Not difficult at all
- 2 A little difficult
- 3 Somewhat difficult
- 4 Very difficult
- 5 So difficult you could not do it

CHFA19

19. How difficult was it for you to walk fast on level ground or climb a flight of stairs because you felt short of breath or tired?

- 1 Not difficult at all
- 2 A little difficult
- 3 Somewhat difficult
- 4 Very difficult
- 5 So difficult you could not do it

Chronic Conditions

SOURCE A20-23: Benson, V., Marano, M.A. Current Estimates from the National Health Interview Survey, 1995: National Center for Health Statistics. *Vital Health Stat* 10:199, 1998.

CHFA20

20. Has a doctor ever told you that you had had a heart attack?

- 1 Yes 2 No

CHFA21

21. Has a doctor ever told you that you had hardening or narrowing of the arteries of the heart?

- 1 Yes 2 No

CHFA22

22. Has a doctor ever told you that you had angina or an-ji-na?

- 1 Yes 2 No

[TRAINING ISSUE: Respondents who have been told they have angina will know it. Also, need to work on pronunciation as part of training.]

CHFA23

23. Has a doctor ever told you that you had a stroke?

- 1 Yes 2 No

CHFA24

24. Have you ever had any of the following tests or procedures?

An echocardiogram? In this procedure a technician smears cold jelly on your chest, puts a microphone on your chest and then looks at your heart on a television screen.

- 1 Yes
2 No
d Don't know

CHFA25

25. A cardiac catheterization or an angiogram? In both procedures a heart specialist puts a tube into your groin and pushes it up to your heart to see if there is any problem with the arteries or the valves of your heart.

- 1 Yes
2 No → **Skip to Question 28**
d Don't know → **Skip to Question 28**

CHFA26

26. An angioplasty? In this procedure a heart specialist puts a tube in one of the arteries in your heart and blows up a balloon to open a blocked artery.

- 1 Yes
2 No
d Don't know

CHFA27

27. Coronary artery bypass surgery?

- 1 Yes
2 No
d Don't know

B. Self-efficacy

Now, I am going to read you some statements regarding how you might feel about your heart failure. For each one, I want you to tell me whether you disagree or agree.

CHFB1

1. I know what I need to do to keep my heart failure under control. (Do you:)

- 1 Strongly disagree
- 2 Disagree
- 3 Neither disagree or agree
- 4 Agree
- 5 Strongly Agree

CHFB2

2. I know how to monitor my heart failure and detect any problems early before they get really bad. (Do you:)

- 1 Strongly disagree
- 2 Disagree
- 3 Neither disagree or agree
- 4 Agree
- 5 Strongly Agree

CHFB3

3. Sometimes I get more short of breath or tired and I don't know why. (Do you:)

- 1 Strongly disagree
- 2 Disagree
- 3 Neither disagree or agree
- 4 Agree
- 5 Strongly Agree
- n R volunteers: Never had this symptom

[TRAINING ISSUE: How to handle respondents who say I get short of breath or tired but I know why.]

CHFB4

4. If my heart failure gets worse, I know what I need to do to make myself feel better. (Do you:)

- 1 Strongly disagree
- 2 Disagree
- 3 Neither disagree or agree
- 4 Agree
- 5 Strongly agree

CHFB5

5. If my heart failure gets worse, I feel scared and want to call my doctor or nurse right away. (Do you:)

- 1 Strongly disagree
- 2 Disagree
- 3 Neither disagree or agree
- 4 Agree
- 5 Strongly Agree
- n R volunteers: Never had this symptom

C. Knowledge and Behavior

SOURCE: Developed by David Baker, MD, Case Western-Reserve University, and Kathy Dracup, Dean, UCSF School of Nursing, and/or adapted from questions developed by David Baker, MD, for the study "Literacy and Health of Medicare Enrollees in a Managed Care Setting," forthcoming.

CHFINT

Next, I would like to find out how much you know about heart failure and its treatment. I'm going to read a question and some possible answers. Tell me which answer you think is correct. If you don't know the answer, don't worry, you can just say "I don't know."

CHFC1

1. Compared to someone without heart failure, a person with heart failure should drink:

- 1 More fluids than usual
- 2 About the same amount of fluids
- 3 Less fluids than usual
- d Don't know

CHFC2

2. Someone with heart failure should weigh himself or herself:

- 1 Every day
- 2 Several times a week
- 3 Once a week
- 4 Once a month
- 5 Only if he or she feels badly
- d Don't know

CHFC3

3. Which is the best definition of heart failure? Would you say:

- 1 Heart failure means that your heart is beating irregularly
- 2 Heart failure means that your heart might stop beating sometime soon
- 3 Heart failure means that your heart is not pumping blood as well as it should
- 4 Heart failure means the same as a heart attack
- d Don't know

4. I'm going to read a list of problems, and I want you to tell me if each one is a sign your heart failure is getting worse. If you don't know the answer, you can just say: "I don't know."

CHFC4@a

a. Is shortness of breath a sign your heart failure is getting worse?

- 1 Yes
- 2 No
- d Don't know

CHFC4@b

b. Is swelling of the legs or ankles a sign your heart failure is getting worse?

- 1 Yes
- 2 No
- d Don't know

CHFC4@c

c. What about headaches? PROBE: Are headaches a sign your heart failure is getting worse?

- 1 Yes
- 2 No
- d Don't know

CHFC4@d

d. Waking up at night short of breath? PROBE: Is waking up at night short of breath a sign your heart failure is getting worse?

- 1 Yes
- 2 No
- d Don't know

CHFC4@e

e. Pain in your joints? PROBE: Is pain in your joints a sign your heart failure is getting worse?

- 1 Yes
- 2 No
- d Don't know

CHFC4@f

f. Feeling more tired than usual? PROBE: Is feeling more tired than usual a sign your heart failure is getting worse?

- 1 Yes
- 2 No
- d Don't know

CHFC4@g

g. Weight gain? PROBE: Is a weight gain a sign your heart failure is getting worse?

- 1 Yes
- 2 No
- d Don't know

[TRAINING ISSUE - Water weight gain]

CHFC5

5. Doctors and nurses often tell patients what their weight should be when they do not have any extra fluid? Do you know what your ideal, "dry", or best weight is?

- 1 Yes
- 2 No → Skip to Question 8

6. If your weight goes up by 4 pounds or more over a short period of time, what should you do?

INTERVIEWER: Code the three things respondent mentions. If response is not clear, probe: Can you tell me more about that? If respondent only mentions one thing, do not probe for more things.

PROGRAMMING NOTE: Make this a code all that apply item.

CHFC6@1

1 Cut back on salt

CHFC6@2

2 Take an extra water pill or diuretic

CHFC6@3

3 Call your heart failure doctor within 24 hours CHFC6@4

4 Call your heart failure nurse within 24 hours

CHFC6@5

5 Go to the emergency room

CHFC6@6

6 Wait until your next visit to tell your doctor or nurse

CHFC6@7

7 Other (specify): _____

d Don't know

CHFC7

7. Do you have a scale at home that works correctly?

- 1 Yes
- 2 No → Skip to Question 8

CHFC7a

7a. How often do you weigh yourself? Is it:

- 1 Every day
- 2 Several times a week
- 3 Once every week or two
- 4 Once a month
- 5 Never

CHFCINT3

Now, I would like to ask you a few questions about some foods you might eat and how much salt they contain. If you don't know the answer, don't worry, you can just say "I don't know".

8. Which of the following foods contain a lot of salt?

INTERVIEWER: If respondent asks if we mean low-salt or regular version of food, say regular version.

	<u>Yes</u>	<u>No</u>	<u>Don't know</u>
CHFC8@1			
a. Hot dogs?	1	2	d
CHFC8@2			
b. Orange juice?	1	2	d
CHFC8@3			
c. Canned vegetables?	1	2	d
CHFC8@4			
d. Bananas?	1	2	d
CHFC8@5			
e. Cheese?	1	2	d
CHFC8@6			
f. Bacon?	1	2	d
CHFC8@7			
g. Crackers such as Wheat Thins or Triscuits?	1	2	d

CHFC9

9. During the last 6 months have you taken specific steps to eat foods that are low in salt?

- 1 Yes
- 2 No → Skip to Question 11

CHFC10

10. How successful have you been at sticking to your plans to eat foods that are low in salt? Would you say:

- 1 Not at all successful
- 2 Somewhat successful
- 3 Very successful

CHFCINT4

For these next few questions, I am going to read you a statement about something having to do with heart failure. For each question, I want you to tell me whether the statement is true or false. If you don't know the answer, you can just say "I don't know."

CHFC11

11. It is safe for someone with heart failure to do light exercise like walking.

- 1 True
- 2 False
- d Don't know

CHFC12

12. Drinking alcohol can weaken the heart's pumping ability.

- 1 True
- 2 False
- d Don't know

D. Patient Satisfaction and Access

CHF CARE DOCTOR

CHFD1

1. These next questions are about the doctor you see most often for care related to your heart failure. Think of this doctor as your heart failure doctor when you answer the next questions.

PROBE, IF RESPONDENT HAS MORE THAN ONE HEART FAILURE DOCTOR: Please answer for the doctor you see most often for your heart failure and who makes more of the decisions about your care.

Is your heart failure doctor:

- 1 A general doctor (family or general medicine)
- 2 A heart specialist or cardiologist
- 3 Or something else (Specify) _____
- d Don't know

CHFD2

2. In the last 6 months, how many times did you visit your heart failure doctor? Is it:

- 1 None
- 2 1 to 3 times
- 3 4 to 6 times
- 4 More than 6 times

CHFD3

3. We want to know your overall rating of your heart failure doctor.

Use any number from 0 to 10 where 0 is the worst doctor possible and 10 is the best doctor possible. How would you rate your heart failure doctor in the past 6 months? (If you saw more than one doctor for your heart please rate the doctor you saw most often)

ENTER NUMBER: _____

CHFD4

4. In the last 6 months, how often did your heart failure doctor listen carefully to you? Was it:

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

CHFD5

5. In the last 6 months, how often did your heart failure doctor explain things in a way you could understand? Was it:

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

CHFD6

6. In the last 6 months, how often did your heart failure doctor show respect for what you had to say? Was it:

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

CHFD7

7. In the last 6 months, how often did your heart failure doctor spend enough time with you? Was it:
- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always? |

CHFD8

8. Some doctors work with a special nurse who helps them to take care of patients with heart failure. This special nurse might help teach you about what to do to take care of yourself, call you or check in with you to see how you are doing, and talk with your doctors about any problems you are having with your heart failure.

Is there a nurse or nurse practitioner who helps you in this way?

- | |
|---------------------------------------------------|
| 1 Yes |
| 2 No → Skip to programming note before Q19 |

CHFD9

9. Think of this nurse as a heart failure nurse when you answer the next questions.

In the last 6 months, how many times did you visit a heart failure nurse? Was it:

- | |
|---------------------|
| 1 None |
| 2 1 to 3 times |
| 3 4 to 6 times |
| 4 More than 6 times |

CHFD10

10. In the last 6 months, how many times did you talk with a heart failure nurse by telephone? Was it:

- | | |
|----------------|---------------------|
| 1 None | 3 4 to 6 times |
| 2 1 to 3 times | 4 More than 6 times |

CHFD11

11. We want to know your overall rating of the heart failure nurse (or nurses).

Use any number from 0 to 10 where 0 is the worst nurse possible and 10 is the best nurse possible. How would you rate your heart failure nurse (or nurses) in the past 6 months?

ENTER NUMBER: _____

CHFD12

12. In the last 6 months, how often did a heart failure nurse listen carefully to you? Was it:

- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always |

CHFD13

13. In the last 6 months, how often did a heart failure nurse explain things in a way you could understand? Was it:

- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always |

CHFD14

14. In the last 6 months, how often did a heart failure nurse show respect for what you had to say? Was it:

- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always |

CHFD15

15. In the last 6 months, how often did a heart failure nurse spend enough time with you? Was it:

- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always |

COMMUNICATION

SOURCE CHFD16-17: Developed by D. Baker, MD, and K. Dracup, RN, PhD, for this study.

CHFD16

16. In the last 6 months, how often did you see your heart failure nurse on the same visit that you saw your heart failure doctor?

- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always |

CHFD17

17. How well do your heart failure nurse and heart failure doctor work together as a team in providing your care? Would you say

- 1 Not well
- 2 Just well enough
- 3 Very well

CHFD18

18. In the last 6 months, did you ever have a problem with your care because your heart failure doctor and nurse did not communicate well with each other?

- 1 Yes
- 2 No
- n Does not apply

PROGRAMMING NOTE: If there is no heart failure nurse, Questions 19-25 need conditional text that asks only about heart failure doctor.

CHFD19

19. Please tell me how much you disagree or agree in general with the following statements about your heart failure doctor and nurse.

I feel my heart failure doctor and nurse have given me choices and options about my heart failure treatment. Do you:

[IF NEEDED: Give me the answer that comes closest to your experience most of the time.]

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree nor agree | |

CHFD20

20. I feel my heart failure doctor and nurse have given me confidence that I can make changes in my life to control my heart failure. Do you:

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree nor agree | |

CHFD21

21. My heart failure doctor and nurse are interested in my questions. Do you:

[IF NEEDED: Give me the answer that comes closest to your experience most of the time.]

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree nor agree | |

CHFD22

22. My heart failure doctor or nurse regularly reviews with me how I am doing in managing all aspects of my heart failure. Do you:

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree nor agree | |

CHFD23

23. My heart failure doctor or nurse worked with me to develop a plan so that I know how to take care of my heart failure.

- | | |
|-------|-----------------------------------|
| 1 Yes | 2 No → Skip to Question 26 |
|-------|-----------------------------------|

CHFD24

24. Do you have a copy of this plan in writing?

- | | |
|-------|------|
| 1 Yes | 2 No |
|-------|------|

CHFD25

25. Did you work with your heart failure doctor or nurse to set personal goals for your heart failure?

- | | |
|-------|------|
| 1 Yes | 2 No |
|-------|------|

PERSONAL DOCTOR

CHFD26

26. A personal doctor is the health provider who knows you best. This can be a general doctor, or a specialist doctor (including your heart failure doctor), or some other health provider. Do you have one person you think of as your personal doctor?

- | | |
|-----------------------------------|--|
| 1 Yes | |
| 2 No → Skip to Question 28 | |

CHFD27

27. Is this the same doctor who helps to take care of your heart failure?

- | | |
|-------|--|
| 1 Yes | |
| 2 No | |

ACCESS TO CARE

CHFD28

28. In the last 6 months, did you call a doctor's office or clinic during regular office hours to get help or advice about your heart failure?

- | | |
|-----------------------------------|--|
| 1 Yes | |
| 2 No → Skip to Question 31 | |

CHFD29

29. When you called during regular office hours, how often did you get the help or advice you needed about your heart failure? Was it:

- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always |

CHFD30

SOURCE CHFD30-31: Developed by D. Baker, MD, and K. Dracup, RN, Phd, for this study.

30. When you called during regular office hours, who gave you the help or advice you needed? Was it:

- | | |
|--------------------------------------------------|----------------------|
| 1 Always your doctor | 4 Usually your nurse |
| 2 Usually your doctor | 5 Always your nurse |
| 3 Sometimes your doctor and sometimes your nurse | |

CHFD31

31. In the last 6 months did any of the doctors or other health providers who treat your heart failure call you to check and see how you were doing without you calling them first?

- 1 Yes
- 2 No

CHFD32

32. The next questions ask about your appointments with your heart failure doctor or nurse. In the last 6 months, did you ever try to get an appointment to see your heart failure doctor or nurse right away to get care for a problem with your heart (like chest pain, difficulty breathing, swelling in your legs, shortness of breath)?

- 1 Yes
- 2 No → **Skip to Question 34**
- n Does not apply → **Skip to Question 34**

CHFD33

33. In the last 6 months, when you tried to be seen for a problem with your heart, how often did you see your heart failure doctor or nurse as soon as you wanted. Was it:

- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always |

CHFD34

34. In the past 6 months, did you get a letter, a postcard, or a call from your doctors or health plan to remind you about appointments?

- 1 Yes
- 2 No

E. Patient Education

[NEW developed by D. Baker, MD, for this study]

CHFEINT

Your health care team is made up of the doctors, nurses, dieticians and others who take care of your heart failure. I'm going to read a list of specific things that your health care team may have talked to you about. For each one, I want you to tell me if anyone from your health care team discussed this with you.

Has your health care team:

	<u>Yes</u>	<u>No</u>
CHFE1@1		
1. Explained what is wrong with your heart?	1	2
CHFD1@2		
2. Explained why you sometimes feel tired, short of breath, or have swelling in your legs?	1	2
CHFD1@3		
3. Explained how your medicines work and the benefits of taking the medicine?	1	2
CHFD1@4		
4. Encouraged you to use a pillbox to help you keep track of or organize your medicines?	1	2
CHFD1@5		
5. Talked with you about techniques for remembering to take your medicine every day?.....	1	2
CHFD1@6		
6. Asked you whether you can afford your medicines?.....	1	2
CHFD1@7		
7. Told you not to use salt when you cook and not to add salt to your food after it is cooked?	1	2
CHFD1@8		
8. Talked with you about which foods are high in salt and which are not?	1	2
CHFD1@9		
9. Told you to avoid drinking alcohol?.....	1	2
CHFD1@10		
10. Told you to avoid drinking large amounts of water or other fluids?	1	2
CHFD1@11		
11. Told you to weigh yourself on a scale every morning and write down your weight?.....	1	2
CHFD1@12		
12. Told you that you should get regular exercise, such as walking?	1	2

Has anyone from your health care team ever:

	<u>Yes</u>	<u>No</u>
CHFD1@13		
13. Talked with you about how your heart condition might affect how long you live?	1	2
CHFD1@14		
14. Talked with you about living wills, durable power of attorney for health care, or other ways of writing down what you would want done if you were ever too sick to speak for yourself?.....	1	2

[TRAINING ISSUE – Respondents who have had a doctor or other provider talk with them about living wills or power of attorney know it.]

	<u>Yes</u>	<u>No</u>
CHFD1@15		
15. Did your doctor or nurse ever discuss whether you wanted CPR performed or to be put on a machine if you stopped breathing?	1	2
CHFD1@16		
16. In the last 6 months, have you gone to a support group for people who have heart failure?	1	2

F. Social Support

SOURCE: D.K. Moser and K. Dracup, "Psychosocial Recovery from a Cardiac Event: The Influence of Perceived Control," *Heart & Lung*, 24(4):273-280, 1995.

CHFF1

1. Does a family member or friend ever remind you to do things to stay healthy, like getting enough sleep or exercise, or taking your medications?
 - 1 Yes
 - 2 No

CHFF2

2. People sometimes look to others for companionship, assistance, or other types of support. Please tell me how you would rate the support you usually receive?
 - 5 Poor
 - 4 Fair
 - 3 Good
 - 2 Very good
 - 1 Excellent

J. Demographics

These next questions are about you and will help us to describe all the patients who take part in this study.

Age and Gender

CHFJ1

1. What is your age now? Stop me when I get to the right category.

1 18 to 24	5 55 to 64
2 25 to 34	6 65 to 74
3 35 to 44	7 75 or older
4 45 to 54	

CHFJ2

2. INTERVIEWER, ASK ONLY IF NECESSARY: Just so I can be sure, are you male or female?
 - 1 Male
 - 2 Female

Race, Ethnicity

CHFJ3

3. How would you describe your race or ethnicity? Are you:
 - 1 Latino or Hispanic
 - 2 White
 - 3 Black or African-American
 - 4 Asian or Pacific Islander
 - 5 Another race or multiracial

Education

CHFJ4

4. What is the highest grade or level of school that you have completed?

PROBE: Did you graduate with a diploma or degree?

INTERVIEWER: Code trade school or technical school as "some college or 2-year degree"

- 1 8th Grade or less
- 2 Some High School, but did not graduate
- 3 High School graduate or GED
- 4 Some College or 2-year degree
- 5 4-Year College graduate
- 6 More than 4-year college degree

Health Insurance

CHFJ5

5. Do you have any kind of health insurance, or are you enrolled in any kind of program that helps to pay for your health care?
- 1 Yes
 - 2 No → **Skip to Question 9**

CHFJ6

6. Do you belong to a health maintenance organization or HMO?
- 1 Yes
 - 2 No

CHFJ7

7. Does your insurance plan or program allow you to go to any doctor you want or does it require you to choose from a group or list of doctors?
- 1 Any Doctor
 - 2 Select from group or list
 - d Don't know

CHFJ8

8. Does your insurance plan or program pay all, part or none of the cost for prescription medicine?
- 1 All of the cost
 - 2 Part of the cost
 - 3 None of the cost
 - d Don't know

CHFJ9

9. On average, how much do you spend out of your own pocket each month on prescription medicine? Is it:
- | | |
|------------------------|-------------------------|
| 0 Nothing | 3 \$51 to \$100 dollars |
| 1 Less than \$20 | 4. More than \$100 |
| 2 \$20 to \$50 dollars | |

CHFJ10

10. In the last 6 months, have you ever had to go without health care or medicine that you needed because you needed the money for food, clothing, housing, etc.?
- 1 Yes
 - 2 No

Utilization

CHFJ11

11. Is (FILL PILOT OR CONTROL CARE LOCATION) the place you go most often for care related to your heart failure?
- 1 Yes → **Skip to Question 13**
 - 2 No

CHFJ12

12. What is the name of the place you go to most often for care related to your heart failure?

ENTER PLACE NAME (Allow 50): _____ **Skip to Q15**

[NOTE: Here is the alternate version of 11-12 for sites in which the control and pilot samples are identified by provider not clinic name.]

CHFJ11

11. Is (FILL NAME OF PILOT OR CONTROL DOCTOR) the doctor you see most often for care related to your heart failure?

- 1 Yes → Skip to Question 13
- 2 NO

CHFJ12

12. What is the name of the doctor you see most often for care related to your heart failure?

ENTER PLACE NAME (Allow 50): _____ **Skip to Q15a**

CHFJ13

13. How long does it usually take you to get to (FILL SITE NAME) from your home or office?

Enter Number: ____ (0-99)

- CODE UNIT: 1 Minutes
- 2 Hours

CHFJ14

14. Have you been going to (FILL SITE NAME) for care for one year or more?

- 1 Yes
- 2 No

CHFJ15a

15a. In the past 6 months, how many times did you go to the emergency room to get care for yourself? (Your best estimate is fine.)

PROBE: Include all of your health care in your answer, not just care related to your heart failure.

Enter Number: _____ (acceptable range is 0-15 times)

CHFJ15b

15b. In the past 6 months, how many times did you go spend one night or more in the hospital? (Your best estimate is fine).

PROBE: Include all of your health care in your answer, not just care related to your heart failure.

Enter Number: _____ (acceptable range is 0-15 times)

CHFJ15c

15c. Think about all the doctor's offices and clinics you've visited for health care in the last 6 months. In total, about how many visits have you made to get care for yourself? (Your best estimate is fine.)
Was it:

PROBE: Include all of your health care in your answer, not just care related to your heart failure.

- | | |
|-----------------|----------------------|
| 0 None | 2 4 to 6 visits |
| 1 1 to 3 visits | 3 More than 6 visits |

CHFJ16

16. During the last month, how many days did your health keep you in bed all day or most of the day?

Enter Days_____ (0-31)

Language

CHFJ17

17. What language do you usually speak at home?

- 1 English → **Skip to Q19**
- 2 Spanish
- 3 Other (Specify) _____

CHFJ18

18. In the last 6 months, how often did you have a problem communicating with your doctor or nurse because of language differences? Was it:

- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always |

Marital Status and Household Composition

CHFJ19

19. At this time, are you married or living with a partner?

- 1 Yes
- 2 No

CHFJ20

20. What is your current living arrangement? Right now, are you living . . .

(CODE ALL THAT APPLY)

- 0 Alone
- 1 With your spouse or partner
- 2 With others who are related to you
- 3 With others who are not related to you

Employment

CHFJ21

21. Right now, are you working for pay?

- 1 Yes → **Skip to Question 23**
- 2 No

CHFJ22

22. Is that because of your health?

- 1 Yes → **Skip to Question 24**
- 2 No → **Skip to Question 24**

CHFJ23

23. During the last month, about how many days of work did you miss because of illness?

Enter Days _____ (0-31)

Income

CHFJ24

24. Now I have a question about total income for you and your spouse or partner. Income can come from a number of sources: like salaries, wages, social security, welfare, dividends, interest, and any other income. Think about your total household income in 1998. Would it amount to \$30,000 or more?

- 1 Yes → **Skip to Question 26**
- 2 No

CHFJ25

25. Would it amount to \$15,000 or more?

- 1 Yes → **Skip to Question 27**
- 2 No → **Skip to Question 27**

CHFJ26

26. Would it amount to \$50,000 or more?

- 1 Yes
- 2 No

Home Ownership

CHFJ27

27. Do you own or rent your home?

INTERVIEWER: If R'S parents or family own the home, code it as "own"

- 1 Own
- 2 Rent
- 3 Exchange work for rent or some other rent-free arrangement

K: STUDY ENROLLMENT AND FOLLOW-UP

We will send you a \$10 check for completing this interview. I want to be sure we have your correct address and phone number. The address I have for you is:

[fill STREET]

[fill CITY] [fill STATE], [fill ZIP]

Is this correct?

- 1 No
- 5 Yes

What is your correct address? ENTER CORRECTIONS OR NEW ADDRESS

Street Address: _____
 City: _____
 State: _____
 Zip: _____

The phone number I have for you is: _____ [fill PNUM]

- Is this correct?
- 1 No
 - 5 Yes

What is your correct phone number? _____

We would like to interview you again by phone about 12 months from now in order to find out about changes in your health and to ask about the care you receive over the next 12 months.

Even if you agree to a follow-up interview now, you can change your mind when we call you next year.

- Do we have your permission to call you back about 12 months from now?
- 5 Yes
 - 1 No

In case we have trouble reaching you next year when we do our follow-up interview we'd like you to give us information we can use to locate you.

- Do you expect to move any time between now and September 2001?
- 1 No
 - 5 Yes

Do you know the address you will be moving to?

INTERVIEWER: ENTER AS MUCH INFORMATION AS R CAN GIVE YOU NOW.

Street Address: _____
 City: _____
 State: _____ Zip _____ Phone _____

We'd like to have the name of a friend or relative who always knows how to reach you. We would only contact this person if we are unable to reach you by mail or phone next year for the follow-up interview. Is there a friend or relative that you always keep in close contact with (other than your husband/wife)?

- 1 No
- 5 Yes

What is his or her name and address?

Name: _____
Address: _____
City: _____
State: _____ Zip _____ Phone _____

What is your relationship to [fill name from above]?

- 1 Friend
- 2 Daughter/Son
- 3 Sister/Brother
- 4 Grandchild
- 5 Other Relative
- 6 Other

That's all of the questions I have for you today. You should receive your \$10 check in the next 4 weeks. We'll send you a letter in fall 2001 to remind you about the follow-up interview. Thank you for your help.

GOODBYE

We respect your decision. To help the researchers in this study, would you mind telling me the main reason you don't want to do the follow-up interview?

ENTER MAIN REASON VERBATIM

That's all of the questions I have for you today. You should receive your \$10 check in the next 4 weeks. Thank you for your help.

END